

House Oversight Committee

October 15, 2013

FOIA and Medical research projects

The public has the right to inspect, copy, or receive copies of public records from public bodies. MCL 15.233(1).

A public body may exempt from disclosure public records that are specifically described and exempted from disclosure by statute. MCL 15.243(1)(d).

The information shared with the Department of Community Health in conducting a medical research project is confidential and must be used solely for statistical, scientific, and medical research purposes. MCL 333.2631.

The information in a medical research project cannot be exhibited or disclosed in any way, in whole or in part, by the Department of Community Health except as necessary to further the medical research project. MCL 333.2632.

A person who discloses medical research project information contrary to law is guilty of a misdemeanor punishable by up to one year imprisonment or a fine of not more than \$1,000 or both, and, if the person who illegally disclosed the information is a Department of Community Health employee, then that person is subject to immediate dismissal. MCL 333.2638

In a formal opinion, the Attorney General determined it is necessary to apply the confidentiality provisions of the medical research project sections of the Public Health Code to FOIA requests. Attorney General Opinion #5500, July 23, 1979.

Several sections of the Public Health Code allow the department to designate an investigation as a "medical research project". These sections of the Public Health Code balance the conflicting interests of individual privacy and the right of the public to know about governmental activities.

This designation exempts the information from being disclosed in legal proceedings, administrative hearings and FOIA requests. The medical research project designation facilitates collection of information from providers and individuals on a voluntary basis by protecting it from disclosure. In public health several factors are considered in this designation, including the harm to individuals by releasing the information and the chilling effect on voluntary disclosure of vital information during investigations.

Since 1996, approximately 140 projects have received the designation. One-third of these projects are department led. Department projects have included mortality reviews (e.g., childhood and young adult asthma, sudden cardiac death in the young, maternal mortality), outbreak investigations such as bath salts and fungal meningitis, linkage of data on HIV and cancer, transmission of blood borne pathogens in a provider office following a Department of Licensing and Regulatory Affairs investigation, and violence-

related information including homicide, suicide, and intimate partner violence. Another 15 designations are related to Fetal-Infant Mortality Reviews conducted at the local level by health departments or other organizations such as hospitals. Other designations have included research conducted on cancer by an academic group funded by the National Cancer Institute as part of its Surveillance, Epidemiology and End Results Program.

Projects collect detailed and sensitive protected health information. Information has been collected from and about drug users as in the bath salts investigation, next of kin interviews in the case of mortality reviews, and extremely detailed medical information as in the case of fungal meningitis where department staff collected thousands of pages of patient information. In the case of fungal meningitis, we were dealing with a novel infectious process, with an unknown course of treatment and follow-up, and where the need for information was urgent. This information contributed to the development of national standards of care that impacted many states.

The project that may have the longest standing designation is the PBB cohort investigation, where the effects of exposure to PBB through ingestion were largely unknown in the mid-1970s. The project received the designation in December, 1975 and retains the designation to this day.